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Interviews with caregivers during acute asthma hospitalisations

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ABSTRACT

Objective: Childhood asthma is complex and poor management of childhood asthma is the leading health reason for pediatric emergency department visits, hospitalizations and missed school days for school-aged children. The purpose of this study was to explore caregiver perceptions of home management of childhood asthma in school-aged children who have been hospitalized for asthma.

Methods: Using qualitative descriptive design with in-depth interviews, we aimed to explore family caregiver perceptions of managing asthma in school-aged children between 5 and 12 years of age.

Results: Data were collected from 17 participants; however, two transcripts were incomplete due to interruption in interview from medical team. The sample consisted of 15 families with child age mean of 8 years, and diagnosed with asthma at 2 years and 8 months. Four experts with asthma and research design analyzed all transcripts and six clear themes emerged. These themes included family or caregiver burden, care coordination, certainty or uncertainty continuum, effort to control, sign or symptom recognition, and trigger recognition. In this article, we defined each theme and identify specific statements from families on daily life when affected by childhood asthma.

Conclusions: The findings of this study confirm and extend results from other studies of caregivers who have school-aged children diagnosed with asthma. This study found that families play a vital role in management of asthma on a daily basis and families often assess the overall management of asthma by all child relations throughout the day. Clinical implications are highlighted within each theme.

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Introduction

Childhood asthma is a management challenge for more than 9 million US children and their families (1). Loss of asthma control and acute severe exacerbations are common in child asthma and are the leading causes of pediatric emergency department visits, hospitalisations and missed school days for school-aged children. Current asthma guidelines recommend that environmental monitoring, trigger avoidance and home symptom self-management are critical for preventing severe exacerbations. Children 5–12 years of age typically need family caregivers to help manage their asthma (2,3). Bellin et al. (2) examined low-income caregivers managing a child with asthma and indicated the need for education and family-based interventions that enhance

communication and collaboration between caregivers and providers. Though family caregivers may face barriers to optimal management leading to exacerbations, though it is often unclear what prevents them from achieving ideal home asthma management or what type of education is needed (2,4,5). Feedback from families has helped identify barriers to effective self-management in other chronic diseases but has not been thoroughly evaluated in childhood asthma. Few studies have examined family caregivers' perceptions regarding home asthma management and the child's asthma outcomes (3,6). Insights from family caregivers are likely to help reduce self-management barriers. Therefore, the purpose of this article is to identify themes from family caregiver perceptions of home management of childhood asthma

in school-aged children who have been hospitalised for asthma.

Methods

This study used a qualitative descriptive design with in-depth interviews to explore family caregiver perceptions of managing asthma in school-aged children. We designed the interviews for the hospital setting. Qualitative description was chosen based on the dearth of studies about family caregiver perceptions of managing childhood asthma and the study purpose, which was to obtain rich, straight descriptions that were low inference and portrayed the study participants' perspectives and experiences (7) on family asthma management.

Sample

We used a purposive sample of 17 primary family caregivers of school-aged children between 5 and 12 years of age who were hospitalised for asthma in acute inpatient units at a children's hospital in a southeastern state. Caregivers were included if their child had the diagnosis of asthma for at least 1 year prior to admission and was prescribed a daily preventive medication for asthma to ensure respondents had ample family caregiver experiences to report. Because we were assessing daily life living with asthma, children with co-morbid conditions (e.g., diabetes mellitus, a behavioral diagnosis) or an intensive care admission requiring intubation in the previous 12 months were excluded. Hospitalisation and daily preventative medications were used as a proxy to diagnose severe or poorly controlled asthma (8).

The sample was recruited during the inpatient stay after informing family caregivers on study plans at the start of the admission process. All family caregivers signed an Institutional Review Board-approved informed consent form prior to the interview. All procedures were approved from the clinical research committee within the hospital setting. Sampling ceased once data saturation or informational redundancy was reached.

Data collection procedures

Data were collected from primary family caregivers of children with asthma, and all participants were interviewed in the hospital in a private conference room using a semi-structured interview guide (Appendix A). Interview questions were open-ended, and study

participants were encouraged to introduce meaningful topics for discussion. Each interview lasted at least 1 h, was audio-taped, and study participants completed demographic and asthma morbidity questions. No data were obtained from the child with asthma, and the child was not present during the interviews. Study participants received a gift card from a general store for participating.

The Demographic and Asthma Severity Questionnaire assessed the caregiver's relation to the child and work status (employed full-time, part-time, or no employment), family structure (single parent, nuclear, or blended) and health insurance (private, public, or no insurance), the child's current age, school grade, gender, and ethnic background (Caucasian, African-American, Hispanic, non-Hispanic-Caucasian, or other) as well as the child's asthma history, including age diagnosed, medication usage, frequency of asthma symptoms, number of emergency department visits and hospitalisations in the past year, and number of school days missed due to asthma in the previous school year. The *Interview Guide* was followed to assess family caregivers on a typical day of managing the child's asthma, their asthma management challenges and difficulties, confidence about their level of knowledge and skill for managing asthma, and what was needed to improve their confidence and skill (Appendix A). The interview guide also focused on what led to the child's hospitalisation.

Data analysis

Four researchers, two pediatric asthma experts (physician and family nurse practitioner) and two experts in qualitative research (PhD RN), analysed the interview data for content and themes to summarise the family caregivers' asthma management efforts, needs, and concerns. Two similar studies and analyses were used to guide this protocol (2,7), and both utilised qualitative approaches to code transcript data with emerging themes and/or sub-themes. In our study, the interviews were analysed in the same order in which they were conducted. Data about asthma management effort, needs, and concerns were isolated and coded, using descriptive tags. We examined the transcripts individually and closely noted any differences within mother and father statements. A codebook defining the tags was developed simultaneously to assist with intra- and inter-coder reliability of subsequent interview transcripts. The coding team met regularly to review the results of individual coding for each participant and to develop and refine the codebook. As

the codebook evolved through analysis of additional interviews, the descriptive tags were grouped as themes and subthemes at higher level of abstraction. Both steps were guided by the principle of staying close to the data and limiting inferences to a low level. The first 10 participants were coded as a group to obtain consensus, support consistency, and maintain a low level of low inference. Messages deemed ambiguous by one or more data analysts were not coded. The remaining interviews were coded individually in teams of two. Any discrepancies between the two coders were discussed further and resolved by consensus by the larger group of analysts. Once all data were coded, they were entered into HyperResearch (9), a qualitative data analysis software program, to assist with sorting and retrieving data by codes to search for patterns across study participants. Data from the Demographic and Asthma Severity Questionnaire were summarised using descriptive statistics.

Results

Data were collected from 17 participants; however, two transcripts were deemed incomplete due to interruption in interview from healthcare team. The sample consisted of 15 families with child age mean of 8 years and diagnosed with asthma at 2 years and 8 months (Table 1). Family caregivers included 13 mothers and 2 fathers with self-identified work status as 70% full-time and remainder part time or no work outside home. Family income majority (70%) was identified to be between \$10,000–50,000. Family ethnicity was self-reported as 29% Caucasian, 29% African-American, and 35% Hispanic. Family structure was 35% nuclear and 65% single family or blended. Self-reported emergency department visits had a median of two visits in the past 12 months with range 0–20 visits. School days missed had a median of 10 days with a range 0–33 days over past year.

The authors individually reviewed each transcript and then met as a team by conference call to categorise themes. Five clear themes emerged. These themes included family or caregiver burden, care coordination, certainty or uncertainty continuum, effort to control, and sign or symptom recognition. We will define each theme and identify specific statements from families on daily life when affected by childhood asthma. Lastly, in the discussion section we add the importance of the clinical implications when managing families and child asthma. It is imperative that clinical practice recognises how families perceive managing asthma outside of the clinical setting and on a daily basis. Asthma is a chronic

Table 1. Demographics.

Child and family characteristics, $n = 15$
Child age, mean: 8 years of age (range = 2 years to 15 years)
Child gender: 9 male, 6 female
Child ethnicity: 60%, African-American, 20% Caucasian, 20% Hispanic
Average age of asthma diagnosis: 20 months
Primary caregiver gender: 13 females, 2 males
Primary caregiver work status: full time 87%, no work outside home 13%
Level of income <\$10,000 = 7%, \$10,000–\$50,000 73%, \$50,000–\$100,000 20%
Family structure: single parent 60%, blended 20%, nuclear 20%

condition and greatly affects life outside of the hospital. The families in this study addressed issues within the school, communication with providers and families, and difficulty understanding the diversity of the triggers involved with asthma care. Presenting this data offers insight to clinical practices managing asthma with intentions to look beyond the clinical settings and see how asthma children and families are affected with the disease and management of the disease.

Family or caregiver burden

Eight of the fifteen study participants provided interview data that was initially coded as ‘Family Burden’. This code was defined as any stressor or strain on the family unit. We measured family or caregiver burden on a continuum with time and effort on one end, and caregiver burden with strains such as financial, social, and time on the other. We categorised family caregivers feeling strain such as, not being able to provide appropriate care due to burden of work or relying on others, missing work with exacerbation, time burden with having to give so many treatments, or financial with costs of meds.

The majority of the participants in which family/caregiver burden was coded were mothers, often single mothers, who were the primary family caregivers responsible for both the day-to-day care of their child with asthma and for coordinating care with others who participate in the child’s care. For example, one mother described the burden in leaving her child with an alternative caregiver.

It’s hard because of work. I work full-time and then I have 2 kids at home. So, half the time he’s with the babysitter. Unfortunately, [with] the situation of income and it is my sister who watches him. But the same time ... she called me that day and told me he didn’t feel good, I didn’t know how serious it was. So I think it’s a matter of I’m not home with him every day and you know, I can’t watch him the way I would like to watch him. So I think [it would] have to actually distribute that information throughout the family that way when they are seeing him they can be aware of signs as well.

Family caregivers who worked outside the home and were able to leave their child with a trusted

family member still felt the burden of providing adequate care and its effect on their ability to work. This burden was recognised as:

So she's at home with my mom. And my mother sometimes [states] she feels like, "I don't want anything to hurt her while ... on my watch." I was at work and she called me ... 'she needs a treatment.' I just started a new job so I'm like trying to talk on the phone quietly and I'm like, 'Okay, Mom, do this. Okay, call me back.' And then I just basically told them and they told me, "Go home, it's more important to care of you child. So, I'm sick of missing work."

Another burden experienced by family caregivers, mostly mothers, is not knowing when they will be able to return to work following an asthma-related hospitalisation and that also, affecting their ability to care for their other children living at home.

I feel like, "Yes, he looks great. ... why is that kid in the hospital? But look at the history and in 2 days I could be back here if we don't get him all the way over the hump. ... I tell my work I am coming back. Oops, now I'm not coming back. I find arrangements for my other child again. Just to say, "Go home right now." Where sometimes another 24 hours can ... I want to go home. I want to be in my bed. I want my daughter with me. But that's not always the best.

Overall, the theme of family and caregiver burden was clearly described in text obtained from patient transcripts. This burden extends beyond the primary caregiver as management also occurs in various settings described. As clinical providers, we must recognise burden perceived to see if we may lessen the effects of managing a chronic condition like asthma.

Care coordination

Eleven of fifteen participants provided data that was initially coded as care coordination. This code was defined as coordinating the child's asthma care with family members and school personnel as well as making sense of asthma care plans and advice from different healthcare providers (10). Care coordination was looked at as a necessary task, but it could also be burdensome and lead to conflict (burden was depicted in previous theme). The line was drawn when others were involved in the coordination of patient's asthma management or care. Additional incidents of care coordination were ascertained in the remaining interview transcripts once the conceptualisation of care coordination was broadened to also include coordinating care of the child with asthma.

The family caregiver for the child's asthma often sought to educate others (including the child) about

the disease in managing the child's asthma in order to gain assistance in the child's care. For example, one primary caregiver explained the necessity for teaching the child with asthma about trigger avoidance:

I'm not going to be there all the time. There is only so much I can do. I cannot always be next to him. I try to warn him, 'Don't walk into a crowd of people who are smoking. People can blow smoke and it can come right into your face.'

Some family caregivers found that efforts to coordinate care can be frustrating and fraught with conflict. For example, one family caregiver described "fighting" with her child over administering his daily asthma medications and another referred to her child as "unhelpful" when attempting to engage the child in asthma management. Another family caregiver who was co-parenting with her ex-husband implied acrimony when trying to coordinate asthma management with him. She reported, "He [child with asthma] was with his dad so whatever they did over there, it's his dad's fault that he's in the hospital."

Family caregivers expressed frustration with the school and healthcare system over a perceived lack of cooperation in coordinating the child's asthma. One family caregiver stated, "After a whole year of missing school because of asthma, they have his asthma machine and everything... And then the social worker calls me to tell me that his file doesn't say he is asthmatic." Another family caregiver described frustration over poor care coordination among different providers in the health care system.

Every time you see a different doctor and they say, 'Oh no, he should not be on this, he should be on that. He shouldn't be on every three hours. He should be two times a day. And he should not do the nebuliser, He should be on the inhaler.' It is frustrating. Why isn't everyone on the same page?

Problems with care coordination resulted in family caregivers shouldering more of the burden for the child's asthma management than may have been necessary if others were more knowledgeable or cooperative. For example, a study participant who was unhappy with how the school handled her son's asthma explained:

I work nights so I am home when he's at school. And I'm not that far from the school. So I would rather that they just call me. Especially now after seeing how bad he was when he got home from school on Monday.

Not surprisingly, problems with care coordination could result in poor clinical outcomes. One study participant, a father but stated he was not the primary

family caregiver for the child's asthma, described a situation where poor care coordination between him, the child with asthma, and the child's older sibling contributed to the child being hospitalised.

When she [the child with asthma] is at my household, her sister is a great help making sure she takes her medication when she's supposed to. I have to put the burden on her sister. Her sister takes a lot off my shoulders. Her [child with asthma] ending up in the hospital was a little bit her part and a little bit my part. She didn't tell me that her [asthma] machine was broken and I did not check to make sure the machine was working and that her medication was being taken.

As demonstrated, care coordination can be either helpful or problematic for the family caregiver. Trying to assist multiple networks to come to the same understanding for care can either be helpful or lead to frustrations. Clinical providers could highlight coordination beginning in the primary settings and reaching out to settings presented in this section.

Certainty versus uncertainty continuum

Many family caregivers verify how care coordination may lead to perceptions of feeling more or less confident with home management of asthma. In 13 of the 15 transcripts, we identified a rich certainty and uncertainty continuum theme. We clarified the definition of this continuum as pertains to certainty or uncertainty about triggers or cause of asthma, interpreting signs or symptoms, making treatment decisions, or general asthma management. Researchers did not identify a clear continuum presented in the literature and would recommend more research to highlight this issue for families managing chronic conditions. This theme and associated statements were assigned when describing this continuum by how certain or uncertain family caregivers perceive they are in managing asthma on a daily basis.

When referring to home asthma management of asthma exacerbations, one participant stated:

"Because after a while when, you know, even though the doctor says, 'Okay, you can give him a back to back now.' You start getting worried and you're sitting there, I've just given my child from every 3 hours to every 2 hours, he's probably had 15 treatments... I'm not doing anything. It's not, he's not getting better. You know, it's so... something else has to give. You know, so that's when I get frustrated cause I don't feel like they do a lot of different things here that I couldn't do at home but you're just not able to do those things, so."

Another concerned that treatments are effective stated:

"Once I do the six treatments a day and I wake up and I hear him coughing while I'm asleep. I can see him like trying to gasp for air."

Another focused on how they struggle to prevent the asthma exacerbations:

"How to prevent it from happening... he's always congested. He's always congested up here. Always has a lot of mucous and stuff. And I pack, I pack travel size tissues in his book bag, I put tissues in his pocket. I blow, make him blow his nose and all that stuff a lot in the morning before I send him off to school to make sure he's clear and stuff. And I remind him to blow his nose throughout the day so he doesn't (get a) cold or anything. Cause, you know, that triggers it too, you know."

A mother of a 5-year-old identified hope that the asthma diagnosis will change with:

"Hopefully, I'm hoping that maybe he'll grow out of it, I don't really know. But since he just recently got diagnosed and I'm hoping that as time goes I can also continue to learn more about it. And I've already learned a few things here and being in the hospital, and then just, I'm sure that as I get more information then I'll grow in my confidence. Right now I'm kind of iffy, that's why when I'm not sure I contact the doctor."

In all, perceptions of certainty and uncertainty emerged throughout the discussions in relation to making decisions or general asthma management. This continuum can range from family caregivers feeling certain or uncertain in managing asthma. As clinical providers, we must work to better understand the concept of certainty when managing chronic conditions in children and expecting the family to participate in this effort.

Effort to control

The effort to control the child's asthma was clearly addressed throughout 13 of 15 transcripts. This theme was assigned to text that pertains to efforts to control anything that potentially triggers an asthma attack and can be further categorised as preventative and prescriptive. Additionally, most thematic findings regarding effort to control focused on caregiver action or management within the effort to control.

One family caregiver of a 4-year-old child focused on medical management stating,

"well her Flovent's very easy. You know, it's a pump. She doesn't work it very well and you know, I let her inhale it 5 times."

This seemed to be a misconception of the family confusing preventative and quick relief medication management.

Another family caregiver connected with the focus on medication management adding,

"I know that's the number one priority, I have to make sure he gets his medicine."

On the other hand, a mother of a 7-year-old stressed how she manages asthma using environmental controls:

"Um, but I mean it's mostly medicine and then just always staying on top of it. Echinacea, Airborne are our best friends, it's like the second someone's sick ... cause he's not exercise induced, he's cold, like getting a cold induced. So, um, just trying constantly stay on that and do vitamins and continually doing research. Like I'm trying to find out should I really start him on magnesium daily or, you know, those kind of things, so. That's about it."

Many efforts associated with control also demonstrated that families focus on recognising symptoms and ways to further control childhood asthma. The effort to control reaches beyond the decision to medicate or not, and is seen in the majority of transcripts reviewed. Decisions on environmental controls and triggers was highlighted as a primary concern for families. These families often address causes of the asthma symptoms and seek to be proactive in the response to control before leading to asthma symptoms or asthma morbidity issues.

Symptom and sign recognition

Thirteen of fifteen participants identified early signs for the child with asthma. The theme of symptom recognition was assigned to text focused on caregiver statements about the symptoms or assessment process for management decisions. This symptom recognition identified family response to symptoms and whether the recognition leads to vigilant watching, family management, or seeking formal healthcare (e.g., ED) (11). One family caregiver acknowledged the need for action once signs appeared,

"he gives me the signs and normally I can give him a treatment or I can give him the inhaler and take care of it."

While others recognised an early cough as a symptom of asthma,

"she starts coughing a lot and then um sometimes like high fever and then with a cough and all that stuff then it starts to congest and then I can see her like she's start to have problems breathing."

and

"Well he starts this cough, this real hoarse cough, like with the echo. So I'm like before we get phlegm in there, let's just give him a treatment".

Consequently, another family caregiver recognised correlations in ear infections with airway disturbances and moved immediately towards the hospital:

"we knew on Sunday morning, cause he had a cold and we found out it was an ear infection that could have set this off. That the treatments weren't working so I immediately took him to the emergency room."

In summary, there appeared to be a sense of recognition, and then action towards relief of the symptoms. By reviewing transcripts and understanding the actions and efforts of the family, clinical providers may initiate more asthma education scenarios for families to better understand asthma and symptom management.

Limitations of the study

Study findings are limited by the small sample size; however, the purpose was to discover rich qualitative, descriptive data through interviews with the family caregivers. By listening to family caregivers managing a chronic condition, we see more into the daily life of living with a chronic condition. We must hear the families and we noted this through discussion and interview time with the caregivers in this study. The interviews, however, were completed shortly after admission to hospital, and within hospital settings. We recognise these are not natural settings and may have somewhat affected the emerged themes due to the chronic condition. Though, questions were associated with chronic condition management which is often primary concern and focus throughout the hospitalisation, we believe that the results demonstrate family perceptions when managing asthma on a daily basis, and clearly disclose the impact of asthma on the family as a unit. This study raises questions that clearly warrant further study in regards to accessibility of and accuracy of asthma knowledge.

Discussion

We recognise that 9 million US children are diagnosed with asthma and this significantly influences the quality of life of the children and all members of their family or social network. This study highlights how asthma is integrated into the daily activities of a family and specific challenges families face when managing asthma. Clinical healthcare providers must identify the impact of chronic conditions on the family

and address daily management issues when organising care to patients. Understanding this information leads to improved education and awareness for the family and allows clinical providers to focus on meeting the needs of the family.

There are few published qualitative studies focused on the caregiver management of chronic conditions on a daily basis. The qualitative findings in this study address the impact on families' day-to-day management of asthma and clearly impacts clinical care of child chronic conditions. This study contributed to the literature on caregiver perception, particularly primary caregivers managing asthma in the home setting and added detailed, comprehensive statements on daily management and responsibilities. The documented qualitative findings presented in this study are reliable with previous works addressing how asthma affects a child's quality of life and adds to family burden (7,12,13). The family burden addressed here gives insight to efforts involved with daily family responsibilities and the integration of asthma management. Based on the data, the requirements for the family are clearly multifaceted and affect significant daily actions within the home and school environment.

Consistent with previous literature, this study addressed the helplessness that families perceive when disconnected with healthcare (7,14–16). The two fathers involved in the study were quick to state that the mothers typically managed the child's asthma and medication delivery. We found this to be reliable with literature and recognised the majority of health care visits are made by the maternal caregiver (3,17). Families often assess the overall management of asthma by all child relations throughout the day, and health care providers must recognise the implication of family assessment. It is significant to note how we objectively assessed how consistent perceptions are with evidence-based knowledge. Themes were evident in the review of transcripts, but one overarching theme emerged as to the stress that asthma causes on the family caregivers and in many cases, this resulted in feelings of vulnerability. This vulnerability must be addressed and further studied before we expect families and children with asthma to benefit from school or community based interventions. We must focus on the needs of the family to provide action steps with a chronic condition and daily management effort.

Conclusions/key findings

By reviewing findings from the transcripts, and examining literature, we make recommendations for management of

chronic conditions such as asthma. Understanding family management of childhood asthma is multifaceted and must include family perceptions particularly when concerns impact family burden and vulnerability. By taking time to talk with family caregivers, we have a detailed qualitative data set on how asthma affects the family on a daily basis. Findings from this study will be used to develop and target interventions to promote successful home asthma management and decrease the number of preventable emergency department visits and hospitalisations.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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Appendix A

Qualitative questions collected via structured interview.

Interview Guide

Managing a child's asthma can be challenging. I am trying to understand what kinds of problems parents have when faced with this task. I have a number of questions about what it is like for you.

1. First, can you tell me what you know about how to control a child's asthma?
2. Can you describe your typical day, including what you do to manage your child's asthma?
 - a. How much time do you spend on x (mention each asthma management activity)
 - b. It is hard to calculate time for some of the things you mentioned, for example you mentioned trying to keep him/her away from _____ (e.g., second hand smoke). Can you tell me how much effort this is?
3. How confident are you regarding your overall ability to manage your child's asthma? Tell me about the things that you are most confident about? Tell me about the things you are least confident about?
4. What makes it hard for you to do the asthma management you described for your child?
5. If you had a chance to get help to doing something to better manage your child's asthma, what would that help look like? What is your understanding as to why your child was admitted to the hospital?

Appendix B

Codebook for AQUA study

	Code	Conceptual definition
1	Effort to control/prevention	Pertains to efforts to control anything that potentially triggers an asthma attack—further categorised as preventative and Rx, action/Rx (note potential overlap with effort to control)
2	Certainty/uncertainty continuum	Pertains to certainty or uncertainty about triggers or cause of asthma, interpreting signs/symptoms, making treatment decisions, or general asthma management
3	Triggers/trigger recognition	Identifies what the caregiver believes are triggers for the child; includes statements about parent beliefs about what are <i>not</i> triggers. (specific triggers are listed next to the code)
4	Symptom recognition Sign recognition	Caregiver statements about the symptoms or assessment process for management decisions Potential subcategories for whether the recognition leads to vigilant watching, family management, or seeking formal healthcare (e.g., ER)
5	Recognition of treatment response	Statements of certainty about how the child is responding or not responding to treatment efforts
6	Action/RX Rescue meds Preventative	Any asthma management action or caregiver treatment further categorised with a descriptive tag of the action taken.
7	Perceived efficacy of RX	Collapse under uncertainty with expanded subcategory for actions and make uncertainty a continuum by changing coding to degree of uncertainty or uncertainty–confidence continuum
8	Contrary to guideline/what is known about asthma	Caregiver belief or action that is contrary to established guidelines about asthma and suggests potential misunderstanding of asthma (e.g., triggers that are not considered as causing asthma symptoms)
9	Consistent with best evidence/guidelines/latest knowledge re: asthma	Caregiver belief or action that is consistent with guidelines or inference related to guidelines
10	Perceived ability to manage	Caregiver statements about level of confidence or lack of confidence in all aspects of asthma management
11	Source of asthma information/self-directed search for information	Caregiver seeks further information; identified source or sources for asthma info; active/passive search
12	Self-reflective	Openness to information that might challenge perceptions about asthma
13	Care coordination Ineffective care coordination	Statements about coordinating or not coordinating care with others in the child's network or with professionals. Links between care, patient, family, system Explanation of frequent consults; differences in medications and dosages; early discharge; rehospitalisation
14	Explanation for ER visit/hospitalisation	Caregiver's explanation for the hospitalisation—includes what caused it and why the decision was made to seek formal health care
15	Fear	Caregiver's response due to worry or anxiety; affective
16	Care (responsibility) transition	Evolution of care from caregiver to child, particularly school-aged child change due to development. Child assumes care-level of responsibility of care transitioning. Shared care
17	Family/caregiver burden	Burdened with any stressing aspects/strains: financial, social, time, resources, emotional, etc. Caregiver effort; continuum with time and effort at one end and burden at end (some time to extensive amount of time). May need expanding!
18	Treatment regimen or effort to control interrupts daily life	Daily care for asthma causes interruption with time and activities; effort to control interrupts daily life.
19	School	Potential subcategories Teacher or school nurse not knowledgeable or level of concern is inappropriate (too much or not enough) School policies, child needs buddy to receive meds from school nurse
20	Help seeking decision making process	Describes a process of making a decision to go or not go to the ED; might include erring on the side of caution
21	Inconsistent Rx plan	Rx plan changes or is inconsistent within and between providers and appears to be based on trial and error
22	Medication concern	Concern (anxiety, worry, unease, disquiet) about use of steroids or over reliance on medication
23	Uncontrollable/out of the caregiver's control	Refers to issues or situations that the parent cannot control, such as the child's exposure to children at school who are sick
26	Caregiver negative emotions	Subcategories: (fear/stress/anxiety) refers to stress or anxiety associated with management of chronic asthma; Family/caregiver distressed
27	Resignation	Feeling resigned-uncontrollable, accepting that asthma is just asthma and can feel out of control